

How Non-Celiacs Changed Gluten Free:
Reshaping Contested Illness Experience in the Gluten-Free Diet Boom

BY

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Submitted to the graduate degree program in Anthropology and the Graduate Faculty of the University of Kansas in partial fulfillment of the requirements for the degree of Master of Arts.

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Date Defended: April 8, 2013

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Date approved: April 8, 2013

Keywords

Gluten free, self-ascriptive looping, illness prototypes, contested illness, food intolerance

Abstract

“Gluten free” exploded onto the American foodscape in recent years, with 30 percent of U.S. adults reducing or eliminating gluten in their diets as of January 2013. In this thesis, I use data from 37 in-depth, semi-structured interviews with gluten-free and -restricted persons to provide a three-part model for the spread of gluten free. Non-celiac dieters popularize gluten free by broadening the lay understanding of the disease, undermining biomedical authority, and diagnosing others. I show how dieters are reshaping the doctor-patient relationship and increasing social contestability for everyone on the diet. My findings challenge previous models of contested illnesses and show how food intolerances may require a reconceptualization of contested illness experience. Finally, I suggest the phenomenon of gluten free helps us understand rising rates of food intolerance in the United States.

Table of Contents

Introduction.....	2
<i>The Rise of Gluten Free</i>	<i>3</i>
Terminology.....	4
Overview of Findings.....	5
Literature Review	7
<i>Food Intolerance and Gluten-Related Disorders</i>	<i>7</i>
Contested Illnesses.....	8
How do medical categories change?	10
Illness Prototypes and the Interpretation of Symptoms	11
Methodology	14
Sampling	14
Study Population.....	14
Data Collection and Analytic Methods.....	14
Results	17
Study Participants.....	17
Illness Prototypes.....	17
Victoria: Anxiety, Energy, and Multiple Sclerosis.....	17
Matilda: Improved Sleep, Focus, and Fertility	18
Sandy: Peace and Eyesight	20
How the Prototype Expanded	21
Undermining Biomedicine	22
Jill: Unresolved issues and an unnecessary scare	22
Michael: Taking Matters into His Own Hands	23
Christy: Questioning Biomedicine’s View of the Life Course.....	24
Diagnosing Others	25
Christy: “List all your symptoms”	26
JoAnn: An audience of 700.....	27
Discussion.....	29
<i>Prototype Change in the Gluten-Free Community</i>	<i>29</i>
Undermining Biomedicine, Subverting the Diagnostic Process.....	31
Diagnosing Others: Shouting from the Rooftops.....	33
The Model	33
Self-Ascription and Contested Illness	34
Gluten-Related Disorders as Contested Illnesses	34
Specter of the Fad Diet	35
Looping to a Changed Doctor-Patient Relationship	37
Conclusion	39
Limitations of the Study	40
References Cited.....	41
Appendix 1	45
Sample Interview Schedule	45

Introduction

Going gluten free used to occur under a doctor's supervision. The restrictive diet was largely unknown in popular culture, and anyone eliminating gluten earlier than a few years ago struggled to find suitable foods or maintain regular social activities (Lee and Newman 2003). Recently, though, it is an increasingly popular dietary option in the United States. As of January 2013, 30 percent of U.S. adults report reducing or eliminating gluten in their diets (NPD Group 2013). Restaurants and grocery stores are beginning to accommodate this trend, and retail sales of gluten-free products have grown almost 28 percent in the last 10 years. They are now a \$4.2 billion dollar market—larger than both low-carbohydrate and fat-free diets (Packaged Facts 2012; Sapone et al. 2012). In addition to increased diagnosis of celiac disease (CD), the autoimmune disorder where gluten-free diets originated, the diet is now used to treat a host of disorders, from fibromyalgia to depression, and is often pursued without medical supervision. The rise in gluten free is nearly absent from social scientific scholarship. How did the uses and popularity of gluten free change so rapidly over the past decade? How do individuals decide to follow a gluten-free lifestyle? This study seeks to answer those questions, as well as examine how these changes challenge gluten-related disorders' (GRD) classification as contested illnesses in social scientific literature.

Gluten is a protein found in wheat, barley, and rye. Gluten elimination originated as the only treatment for celiac disease, an "autoimmune disease that damages villi in the small intestine, preventing proper absorption of vitamins and minerals" (Copelton and Valle 2009). Until recently, medical professionals thought celiac was rare in America. As late as 1999, medical textbooks suggested only 1 in 10,000 Americans had the disease. In 2003, a large epidemiological study shocked the medical world by showing one in 133 Americans have celiac disease (Fasano et al. 2003). Following the study, both health care professionals and the general

public started to pay attention to gluten (O'Brien 2011).

In this study, I show how gluten free expanded beyond its origin as a biomedically prescribed diet for the treatment of celiac disease. Non-celiac dieters push the diet away from biomedicine by broadening the lay understanding of the disease, undermining biomedical authority, and diagnosing others. Dieters are reshaping the doctor-patient relationship and increasing social contestability for everyone on the diet. This study contributes to literature on contested illness and emergent scholarship on food intolerance. My findings challenge previous models of contested illnesses and show how food intolerances may require a reconceptualization of contested illness experience. Finally, I suggest the phenomenon of gluten free helps us understand rising rates of food intolerance in the United States.

The Rise of Gluten Free

While diagnoses of celiac disease have increased dramatically in the past several years, the number of non-celiac gluten-free adherents has also increased. A panel of 15 experts from seven countries met in 2011 at the First International Consensus Conference on Gluten Sensitivity (Consensus Conference) to develop a new nomenclature for these non-celiac conditions (Robinson 2012). The conference report (Sapone et al. 2012:1) addressed the dramatic increase in gluten free around the world.

We are observing another interesting phenomenon that is generating great confusion among health care professionals. The number of individuals embracing a gluten-free diet (GFD) appears much higher than the projected number of celiac disease patients, fueling a global market of gluten-free products approaching \$2.5 billion (US) in global sales in 2010. This trend is supported by the notion that, along with celiac disease, other conditions related to the ingestion of gluten have emerged as health care concerns.

Following medical literature, I use the term “gluten intolerance” to encompass the multiple ways GRDs can manifest clinically. It includes celiac disease, non-celiac gluten sensitivity (NCGS), and wheat or gluten allergy. NCGS is the newest of these classifications. A

non-autoimmune disorder most commonly described as difficulty digesting gluten, NCGS was first formally recognized at the consensus conference. Research on gluten sensitivity is still in its infancy. Researchers are still working toward diagnostic tools and a precise definition of the disorder, along with diagnostic tools. Conference reports show a wide variety of symptoms of NCGS, including non-intestinal symptoms. This was a shift away from earlier literature that identified gluten intolerance symptoms as primarily gastrointestinal (Sapone et al 2012).

In addition to these categories of gluten intolerance, a gluten-free diet (GFD) has become increasingly popular to treat other disorders. Medical professionals are skeptical of such uses of the GFD. Official consensus conference reports (Sapone et al. 2012:7) underscore these attitudes.

The market is filled either by people who undertake the diet as occasional consumers (no medical necessity) or by individuals affected by maladies *that have been claimed to be affected by gluten exposure*, including autism spectrum disorder, attention deficit hyperactivity disorder, multiple sclerosis and irritable bowel syndrome, *but for which there is no evidence of the effectiveness of the diet*. [emphasis added]

How do individuals decide to follow a GFD in the face of medical skepticism? Why has such a restrictive diet grown so rapidly apart from celiac diagnoses?

Terminology

I use both “gluten free” and “gluten-free diet” to describe participants’ diets. Both of these terms encompass a lifestyle of gluten avoidance. Wheat is foundational to the American diet, and participants described an entire lifestyle shift to incorporate the dietary change. Many had to re-learn how to shop for groceries, cook for their families, and socialize with friends. For some participants, the changes extend to non-food products such as toothpaste or lotion. The term “gluten free,” therefore, speaks to the myriad habit changes accompanying gluten avoidance that make it more profound than single-ingredient substitution or removal.

Rather than use the term “gluten intolerance,” which has a particular biomedical definition, I use the term “gluten-related disorder” (GRD) to describe the range of reasons

research participants followed a GFD. This term includes many disorders implicating gluten, including medically recognized disorders such as NCGS and non-medically recognized ones like psoriasis and autism. This choice of language reflects 95 percent of participants who went gluten free for medical reasons. The remaining 5 percent began the diet for non-medical reasons and subsequently identified medical reasons to continue. Despite media attention to non-medical gluten-free dieting, the medical rationale ubiquitous in my study supports my use of the term GRD.

Overview of Findings

I conducted this study to understand *how* gluten free grew in popularity as a self-treatment for various GRDs, or as a non-necessary dietary choice. The “looping effect” (Hacking 1995) is a useful conceptual tool to understand how scientific categories change over time. The looping effect describes how categories—what Hacking calls “human kinds”—change as experts continually redefine the category’s original boundaries around an ever-changing population.

This study contributes to research on the looping effect by presenting a new form of looping: one driven by self-diagnosis—what Hacking (1995) calls “self-ascription”—rather than by shifting expert knowledge. First, I identify three interrelated mechanisms of self-ascriptive looping. Then, using gluten free as a case study, I show how lay-driven looping reshapes the doctor-patient relationship and can raise the public atmosphere of social contestability for those on the diet.

Non-celiac gluten-free participants expanded the diet in three ways. First, they added new symptoms to the disorder’s illness prototype. Originally developed in the field of health psychology, an illness prototype outlines symptoms commonly associated with a given illness (Bishop and Converse 1986). Gluten-free adherents broaden this prototype by adding new symptoms based on their own unexpected symptom relief.

Second, some participants actively sought to diagnose gluten maladies in others. They see the symptoms of gluten intolerance in the world around them and *persistently* suggest others try the diet. Though a minority of participants engaged in this practice, they were highly vocal and persistent. Third, participants undermined biomedicine by discussing negative experiences with medical professionals and questioning medical knowledge about the body.

The process of self-ascriptive looping, driven by the three-part model I detail, calls attention to other food intolerances. Rates of self-reported food intolerance are on the rise around the world (Crawford 2010; Nettleton et al. 2009). Social scientists can use the findings presented here to consider the social and medical effects of increasingly popular diets used to treat these intolerances among the U.S. population.

Literature Review

Food Intolerance and Gluten-Related Disorders

Work on food intolerance has only appeared in social science literature in the last five years (see Nelson and Ogden 2008; Nettleton et al. 2009; Nettleton et al. 2010). Much of this work has been done in the United Kingdom; none by cultural anthropologists. The lack of research is a concern in the face of rising rates of—and popular attention to—food allergies and intolerances (Nettleton et al. 2010:290). This study speaks to that gap.

According to Nelson and Ogden (2008:1039), the lay and medical worlds are at odds over food intolerance. Medical professionals are skeptical because of unclear etiology and diagnostic tools (Nelson and Ogden 2008; Nettleton et al. 2010). Medical literature in the last two years affirms the existence of some food intolerances, but continued diagnostic ambiguity inhibits full medical legitimation (Sapone et al. 2012). Medical studies regularly report low rates of “true” intolerance (less than 5 percent of the adult population), while self-reported intolerance is on the rise. In 1996, approximately 16 percent of Americans self-reported a food intolerance (Nelson and Ogden 2008:1039); in 2010, the number was closer to 25 percent (Crawford 2010). “While the scientific community debate [sic] the etiology, mechanism, definition, and diagnosis of food intolerance and claim a low prevalence rate, a large number of the general public not only believe they have a food intolerance but are changing their eating behavior accordingly”(Nelson and Ogden 2008:1039).

Food intolerance can be socially problematic because of delayed, non-fatal, and often invisible symptoms. Food allergies, by contrast, present acute, sudden reactions (Nettleton et al. 2010). In general, medical professionals understand food allergies as “pathologically and clinically legitimate,” while food intolerances are not (291). Food intolerances are also contested

socially. “Avoidance of foods because of food intolerance is associated with alternative and unconventional lifestyles, fashion, and trends....Being considered a ‘fussy eater’ is viewed as socially problematic” (297). Lack of medical legitimacy aligns food intolerance with the experience of other patients with medically unexplained symptoms (Nettleton 2006). Furthering the connection between food intolerance and contested illness are the “claims...implicating food intolerance in chronic and recurring conditions such as chronic fatigue syndrome” (Nelson and Ogden 2008:1038).

Copelton and Valle’s (2009) work, one of the first in the social sciences to treat the experience of celiac disease or the GFD, focuses on the multiple paths to diagnosis taken by celiac sufferers. The authors show disparities between lay and medical standards of diagnosis and reiterate the importance of scientifically legitimating illness. The non-medical treatment of celiac disease (a gluten-free diet) allows for self-diagnosis and scientific self-diagnosis alongside conventional medical diagnosis. Scientific self-diagnosis is the “patient directed use of scientific data to self diagnose,” through activities such as “direct-access testing, which allows patients to order laboratory tests without physician requisition” (Copelton and Valle 2009:624). Patients use scientific self-diagnosis to act on symptoms and challenge medical ways of knowing, reflecting a wider trend toward consumer-driven medical care (623). Copelton and Valle’s work is an important start to understanding the rising tide of celiac disease. My research contributes to this literature by expanding the focus beyond celiac disease to include all GRDs and non-medical adoption of the GFD.

Contested Illnesses

“Contested illnesses” refers to a group of illnesses such as fibromyalgia, Gulf War syndrome, and chronic fatigue syndrome that are regarded as less legitimate—both socially and medically—than diseases with a clear etiology and diagnostic framework (Counts 2011). They

are often characterized by a constellation of vague, seemingly unrelated symptoms that lack a clear organic origin (Barker 2008). Sufferers have to fight for a proper diagnosis, treatment, and accommodation, leading Dumits (2006) to describe them as “illnesses you have to fight to get.”

Barker (2008) describes how patients rely on electronic support groups for information and advice on their illnesses.

In an effort to provide answers and solutions to their problems that are consistent with their subjective experiences, laypeople become “citizen scientists” or “patient experts” on their own behalf. This includes drawing on embodied knowledge to challenge medical expertise and producing logical accounts of their own distress.

Contested-illness sufferers have a paradoxical relationship with doctors. They criticize doctors for their skepticism and deride medical professionals in discussion board posts. However, they rely on doctors’ expertise to diagnose and treat them because they are unable to adequately treat themselves. As a result, contested illness groups are often highly active in calling for medical attention to their disorders and bringing them into the fold of medical legitimacy.

Copelton and Valle (2009:624) present celiac disease as a contested illness. While it “is a medically accepted condition with a clear biomedical definition and diagnostic criteria”—unlike other contested illnesses—patients’ experiences of misdiagnosis and medical uncertainty share much in common with diseases such as fibromyalgia (Barker 2008) or chronic fatigue syndrome (Dumit 2006). Internet support groups promote mistrust of doctors and encourage celiac patients to self-diagnose. Such groups help patients request the right tests, locate sympathetic physicians, and interpret results. As the title of Copelton and Valle’s (2009) work suggests, however, celiac patients are far less bound to doctors than other sufferers because “you don’t need a prescription to go gluten free.”

How do medical categories change?

Hacking's (1995; 2007) looping effect describes how categories are continually redefined as the people within them change. The process has implications for the perception and experience of a diagnosis. The looping effect is a form of "classificatory feedback" between people and their classifications (Hacking 2002:10) The process of classification changes people, either because of what they believe about themselves or because of how others respond to them. New classifications open up new "ways of being," of experiencing oneself, and can result in behavioral changes.

Amassed changes mean the people classified are different than when the classification was originally applied. As a result, the experts who applied the original category must redefine the classification to fit those within it (Hacking 1995). Changes to categories, the categorized, and subsequent categories can continue *ad infinitum*.

The looping effect challenges the idea of "natural classifications" of people. Medical and psychological sciences in particular seek classifications that mirror the natural sciences—as, for example, in research on pathologies such as schizophrenia, the search for the "homosexual gene," or work to locate causes of violence in the brain. However, because classification has meaning for human subjects, it cannot mirror natural science's work on "indifferent subjects" such as dirt or rocks. The interactive nature of people and their classifications results in a "moving target" (Hacking 2002:11).

The looping effect has been used to examine learner categories such as dyslexia (Davis 2008), multiple personality disorder (Hacking 1995), and autism (Hacking 1999; Rossi 2012). Work on autism (Rossi 2012) connects the looping process with changing illness prototypes. The process of looping creates new prototypes for clinical diagnosis of autism. Diagnostic instruments developed and later abandoned reflect changing prototypes. A historical view of

these instruments also shows how the looping process “alternat[ed] the privileged status of parental and clinical expertise over time.” Rossi’s work highlights a key feature of much looping scholarship: the heavy reliance on experts for definition and redefinition of categories. Indeed, the role of expert is integral to the whole process. “Experts create or modify classifications that are assigned to individuals who subsequently internalize them and make them their own. At the same time, the new behavior of the classified persons creates a reality that the experts must contend with in terms of their classifications” (Rossi 2012:11).

This model has deficits. How do we account for people who categorize themselves? In the case of gluten avoidance, some—especially celiacs and those diagnosed with NCGS—may have the label applied *to* them. Others, however, self-ascribe the label; they join the group voluntarily. Hacking (1995:382) briefly acknowledges this deficit and predicts self-ascriptive human kinds will “lead to a wholly new type of looping effect.” My research on non-celiac gluten-free dieters shows how looping occurs through self-ascription, much as Hacking predicted.

Illness Prototypes and the Interpretation of Symptoms

Bishop and Converse (1986:97) first theorized illness prototypes as:

Fairly well-structured and stable representations in memory of the symptoms and other attributes associated with particular disease entities. These disease prototypes are conceptual representations that serve as standards against which to match and evaluate information about symptoms being experienced.

Rather than being fixed definitions, prototypes are the best example in a broader field of family resemblances (Hacking 1995). Prototypes “are not mere supplements to definitions. They are essential to comprehension. One can make a very strong argument...that what people understand by a word is not a definition, but a prototype and a class of examples structurally arranged around the prototype” (Hacking 1995:23-24). Illness prototypes are essential to the

conceptualization of illness.

Kirmayer and Sautorius (2007) describe the importance of illness prototypes in shaping illness expression and people's perceptions of their bodies. People interpret symptoms as problematic based on illness prototypes and ignore symptoms without a corresponding prototype. Bishop and Converse (1986) support this claim, noting people experience physical symptoms on a regular basis, but only seek treatment for some of them. The symptoms individuals problematize align most closely with a recognized illness prototype.

As discussed in the previous section, illness prototypes have been used to explain clinical diagnosis of autism. Prototypes enable clinicians to diagnose autism rapidly. Rather than relying on diagnostic criteria presented in the DSM, psychiatric residents diagnose autism through tacit knowledge of prototypes. They simply know what it "looks like" (Rossi 2012:109).

Hacking's (1995) study of multiple personality disorder (MPD) shows how illness prototypes change as expert knowledge changes. Prototype change is more than conceptual. It significantly affects the experience and treatment of a disease. For example, when child abuse was incorporated into the prototype of multiple personality disorder, it caused dramatic change in the social and clinical experience of the disorder. Originally, child abuse was not linked to MPD because child abuse was not itself a medical category. When child abuse became part of the MPD prototype, diagnosis and treatment patterns changed radically. Practitioners began working with patients to uncover repressed memories; patients defined themselves through recovered memories.

Most important for my analysis of gluten-related illness prototypes, Hacking's work foregrounds the role of experts. Changes in expert knowledge can have profound impacts on diseases and sufferers. Considered alongside Kirmayer and Sautorius (2007) and Bishop and

Converse (1986), Hacking's work shows the importance of illness prototypes and the wide-reaching impacts of prototype change. I examine prototype change to understand the rapid change in gluten free. I can then consider possible impacts of that change.

Contested illness literature shows self-help groups rely on broad illness prototypes for defining contested disorders (Swoboda 2006). Termed "permissive illness narratives" or "permissive symptomologies," these broad categories foster self-diagnosis among contested illness sufferers. This is salient for self-diagnosed and scientifically self-diagnosed celiacs, who easily identify themselves in long lists of possible symptoms of the disorder. Permissive symptomologies develop as laypeople "recogniz[e] symptoms and abnormal bodily experiences, link symptoms with external stimuli, and construct explanations that borrow heavily from medical science, appropriate medical language, and posit unique social and biological etiologies" (Copelton and Valle 2009:625-6). While permissive symptomologies are useful for understanding the process of self-diagnosis, the concept does not explain how these symptomologies broaden over time. I suggest changing illness prototypes fill that conceptual gap.

Much like previous work on the looping effect, social science literature on illness prototypes relies primarily on expert-driven change. In the present study, however, expert knowledge is only one factor in the rapidly changing GRD prototype. I propose a model for lay-driven prototype change based on my research participants' experiences. This model is a key mechanism of the self-ascriptive looping I describe in this thesis.

Methodology

Sampling

For this study, I conducted 37 in-depth semi-structured interviews over six months in 2012. Of the 37 participants, 31 had not received a formal diagnosis of celiac disease. I used those 31 interviews as the primary data for this study. The participants with celiac disease provided background and contextual data.

Study Population

I conducted this research in Lawrence, Kansas, a midwestern university town of 89,000 people. Most participants lived in town, though some came from neighboring areas. Services available in Lawrence draw dieters from hours away. Mainstream grocery chains and two natural foods grocers carry extensive gluten-free selections. A host of restaurants accommodate dietary restrictions. A well-known naturopathic practice is also located in the town.

Lawrence is in the top 10 cities for per capita Bachelor degree attainment nationally, with 52.8 percent of people over age 25 possessing a Bachelor's degree or higher (US Census 2010). Education of research participants exceeded even this high figure. Eighty-two percent of participants over age 25 had at least a bachelor's, and 36 percent had a Master's degree or higher. These numbers exclude the three participants between ages 18 and 24, all of whom were students (see Table 2). It is unclear whether this is a sampling artifact, based on who encountered and responded to posted advertisements. However, this is in line with research suggesting self-diagnosis of other contested illnesses occurs more frequently among those with higher education (Vierk et al. 2007). Table 2 displays the distribution of participant household income.

Data Collection and Analytic Methods

Participants were recruited through fliers in stores and restaurants, word-of-mouth, a

classified ad, and area gluten-free events. Interviews (see Appendix 2 for sample interview schedule) were conducted at a site of the participant's choosing, most frequently a coffee shop or cafe. Interviews were semi-structured and included questions like: "How did you first learn about gluten-free diets?" and "How did you decide to go gluten free?" After transcribing the interviews, I analyzed them in a two-step inductive coding process. First, transcriptions were coded using an open-coding method. Next, I applied focused codes based on four themes that arose during open coding: (1) negative experience with a doctor, (2) undermines biomedicine, (3) unexpected relief of symptoms, and (4) diagnoses others.

Table 1: Characteristics of Participants without a diagnosis of celiac (top) and a breakdown of “Non-celiac gluten free” by reason for going gluten free among the 31 non-celiac participants (bottom)

Demographic Information: All Participants	Diagnosed Celiac	Non-Celiac
Male	0	5
Female	6	26
Median Age	51.5 years	41 years
Median length of time gluten free	72 months	14 months
Characteristics of “Non-Celiac Gluten Free”	#	%
Self-diagnosed celiac disease	4	13%
GRD diagnosed by alternative practitioner	5	16%
Self-diagnosed GRD	6	19%
GRD diagnosed by MD	8	26%
Gluten free for other reasons: Weight loss, Anxiety, Colitis, Autism, etc.	8	26%

Table 2: Education and household income information for 31 non-celiac participants

NCGF Highest Level of Education	# of Participants	%
High school or GED	2	6%
Some College	6	19%
Bachelor’s degree	13	42%
Master’s degree	8	26%
PhD	2	6%
Total	31	100%
NCGF Household Income	# of Participants	%
Below \$25,000	5	16%
\$26,000-50,000	8	26%
\$51,000-75,000	4	13%
\$76,000-100,000	5	16%

Results

Study Participants

Table 1 describes participants' demographic characteristics. Since non-celiac gluten-free dieters are the focus of my study, I provide a breakdown of the term in Table 1. "Non-celiac gluten free" includes self-diagnoses, diagnosis of non-celiac disorders, and a range of other motivators.

Illness Prototypes

Victoria: Anxiety, Energy, and Multiple Sclerosis

Victoria is a married graduate student with two children. She initially investigated gluten as a cause for her 11-year-old son's stomach problems. Since her mother was diagnosed with celiac several years earlier, Victoria was aware gluten might be a problem for her family. Her son tested negative for celiac, and Victoria asked her doctor about other gluten-related disorders. The doctor was unable to answer her questions. Victoria's chiropractor recommended the family eliminate gluten for two weeks. "Within the first three days, I was like 'Oh my goodness, I have not felt this good since I don't know when.'" She realized her lifelong problems with anxiety were likely linked to gluten, as were her stomach problems.

Over my life, I've had stomach problems, but I just thought "Oh, it's just something that is normal." It went away. So within three days I was just like, "Wow. Something is up here." My head also just kind of cleared up. The other really interesting thing was that, within seven days, I no longer needed to drink three cups of tea a day. If I drank one cup, I was almost too awake. Since I have been on the gluten-free diet, I have not needed to drink caffeine anymore. That's what personally happened to me.

In addition to her unexpected changes, Victoria reported that the diet greatly improved her daughter's eczema, her son's digestive problems and anxiety, and her husband's seasonal allergies. She said her whole family seems less susceptible to seasonal viruses. The children, who used to get sick almost monthly, rarely fall ill. Victoria tells her friends and family about

these positive changes, and she takes them into account when suggesting the diet to others. Even though she sometimes feels uncomfortable making recommendations, she says, “Sometimes you can’t help it. If it’s related, you could really help someone.” For example, her research suggested a connection between gluten and immune-related diseases. This was not incorporated into her illness model through her own experiences, but through another’s account; in turn, she passed it to her neighbor.

The person who I am happiest to have talked to about it is my neighbor, who has MS [multiple sclerosis]. I’d just read *Dangerous Grains* and read about how connected gluten is to immune diseases, so I suggested it to her. She came up to me a month later and was like, “Oh my gosh! I just wanted to tell you!” She finally tried it and said she felt so much better. She’s a nurse, so if she had good results she might be passing it on.

In this comment, Victoria acknowledges the role of personal dietary success in the spread of awareness about the diet’s benefits. She also demonstrates how relief of symptoms—whether her own or another’s—can become part of a prototype. When recommending the diet to others, Victoria’s anxiety, energy, and clear thinking are part of her narrative. She will also pass along benefits she has not personally experienced, such as relief of multiple sclerosis. She anticipates her neighbor will reinforce the addition of these new prototypical symptoms as she relates her experience to others.

Matilda: Improved Sleep, Focus, and Fertility

Matilda, a stay-at-home mother in her early 40s, was excited to talk about myriad symptoms the diet had relieved for her and her 6-year-old daughter Amy. They originally went gluten free after suspecting it was causing her daughter’s extremity numbness. Matilda had read about possible connections between Type 1 diabetes and celiac disease. She feared Amy was at risk. Though she had not been diagnosed with celiac disease (or any gluten disorder), Amy showed signs—such as numbness—that Matilda identified with the onset of diabetes. Matilda’s personal motivation for the diet was weight loss. She felt she would be healthier without gluten

in her diet. Reading the book *Wheat Belly* (Davis 2011) convinced Matilda gluten does real harm to her family's health. Even though she expected to feel better, Matilda reported surprise at the diet's effect. She discussed her newfound energy, improved sleep, and her daughter's changes:

The fatigue is pretty much gone. My thoughts are clearer, I used to have a little bit of haziness in my thinking at certain times. I used to have a lot of low blood sugar moments, and she did too. Those are pretty much gone.

She described how, within weeks of eliminating gluten, she could get out of bed more easily than at any previous time in her life. Both she and her sister experienced this change.

After a couple of weeks, I woke up at six and I was ready to get up. Now, I don't go to bed until midnight and I get up at 7:30. I know that's seven-and-a-half hours, which I know is more than a lot of people get, but it's less than I've ever required in my life. Now, I get out of bed a lot easier, I want to get up. My sister went off of gluten too, and I remember she called me...and said that she wasn't having a hard time getting out of bed anymore.

In addition to these changes, Matilda saw remarkable improvement in her daughter Amy. Previously, she had been losing her hair; what remained was thin and brittle. Amy was restless and had a hard time focusing on tasks. After eliminating gluten, Matilda said Amy's hair improved, as did her attention. She reported: "It seems a lot easier now to sit down and teach her something, or even sit down and read a book. She's always loved to read books, but...you had to sit there and she was floating around the room while you were reading a book, and now she'll sit on your lap forever."

Matilda believed her self-diagnosed gluten intolerance was the problem underlying years of infertility. Before Amy's birth, Matilda suffered multiple miscarriages. Amy was two months premature. Though Matilda will not attempt another pregnancy, she believes eliminating gluten would make it possible. She tells others about the connection between gluten and infertility, as well as the other benefits she and her daughter have experienced. She encourages others to give up gluten for a month, just to see if it helps. Her experience has been so powerful she

recommends eliminating gluten even without evidence of a disorder. Her three adopted children, for example, do not show signs of a GRD. Yet, Matilda believes it important they eat as little gluten as possible.

Matilda's excitement about the benefits of going gluten free, alongside her concern about gluten's potential harm for everyone, suffuses her narrative. Her experience highlights symptoms absent from the classical illness prototype: poor sleep, infertility, hair loss, ADD-like symptoms, low blood sugar, hunger, and weight gain. With each retelling of her dietary success, Matilda bolsters these symptoms' place in the new illness prototype for a GRD.

Sandy: Peace and Eyesight

Sandy was also pleasantly surprised by the diet's effects. Initially, she and her husband went gluten free for weight loss: "We started out, we read the title of a book—we didn't even read the book—it was *Lose the Wheat, Lose the Belly*. So, that convinced me. We decided we'd go wheat free." Her husband eventually read several books about gluten, and they transitioned from wheat free to gluten free. Following the transition, Sandy's blood pressure stabilized and her hot flashes diminished: "I think overall there's less gas, there's less of a jittery feeling, and I'm more peaceful." Most dramatic, however, was her eyesight.

Two weeks after going wheat free...I'd been reading large print books at the library. Because the words would dance on the page if I got real tired. [Now] I'm reading regular print books. It's definite, because I could NOT read a regular print book [before]. And newspapers, it was so difficult...It was just so sudden, and so sure...I will say, it is because I'm gluten free. It's just like the library opened up a whole new room for me! I didn't know that there were so many books that were not made large print. I'm having fun with that.

Sandy felt so pleased with the diet she maintained it, even without the weight loss she expected. Her husband, too, is passionate after losing 18 pounds and experiencing his own unexpected relief. They both talk about their experience with others and try to raise awareness among their friends and family, especially those with health problems.

How the Prototype Expanded

Such narratives, representing 55 percent of my research participants' experiences, illustrate how gluten free continues to change. When these participants felt an improvement in their energy, skin, or eyesight, how they understood those feelings changed. Before, they did not identify their tiredness or vision as unusual, or indicative of a larger problem. After going gluten free, these participants recast those everyday bodily experiences as symptoms. Through their narratives, they add to the list of possible symptoms of a GRD. A gluten-free diet can solve the classic problems: diarrhea, lethargy, and bloating; it is also used to treat vision problems, hair loss, low blood sugar, and poor sleep. Many participants who experienced change also preached the miracle of gluten free to others, encouraging the diet for their symptoms. In this way, the illness prototype for gluten grows. The list of gluten-related symptoms is now nearly comprehensive—everything from irritability or schizophrenia to diarrhea to lethargy.

The three case studies presented here are women, but men's narratives reflected the same prototype change. David realized his figure was not just his body type: "I watched my grandfather and uncle have a pot belly. I thought, 'Well, that's the pot belly I'm going to have.' But then it went away, and I was like, 'Oh!'" Reflecting on the rise of gluten free, he said many people would not realize they were sick until they tried the diet. "The symptoms are so vague, if you didn't treat them, the person would just be considered a slow, tired person, not necessarily a sick person." As the illness prototype expands, more people recognize tiredness as pathological and, ultimately, treatable.

Books are featured in all three case studies. Yet, only seven participants mentioned reading about gluten in a book. Books on this topic are proliferating, but the most influential appears to be *Wheat Belly* (Davis), published in 2011. Six of these seven read *Wheat Belly*, and were convinced by the argument Davis presents. Their descriptions of the book closely mirrored

narratives of unexpected relief. In part, this seems to be related to the book's narrative style.

Davis (2011) uses anecdotes from his patients, reporting his surprise at their unexpected relief of symptoms.

It was the *other* results they [my patients] described that took me by surprise: **weight loss of 25 to 30 lbs over several months, marked improvement or total relief from arthritis, improvement in asthma sufficient to chuck 2 or 3 inhalers, complete relief from acid reflux and irritable bowel syndrome symptoms, disappearance of leg swelling and numbness.** Most reported **increased mental clarity, deeper sleep, and more stable moods and emotions.** I witnessed even more incredible experiences like the 26-year old man incapacitated by full-body joint pains who started to jog again, pain-free. That's when I knew that I had to broadcast this message. *Wheat Belly* was the result. [Davis 2010, emphasis in original]

Davis's narrative reiterates the unexpected relief experienced by so many participants. Though he is a doctor, he sets himself apart from other health care professionals by challenging medical recommendations for a diet rich in whole grains. This position allies him more closely with the lay prototype than the biomedical one. For participants who read and cited Davis (2011), I grouped symptoms learned through *Wheat Belly* along with the prototype expansion resulting from person-to-person narratives.

Undermining Biomedicine

When participants talked about their diets, they did more than add to the collective illness prototype. Participants' narratives also undermine biomedicine by relating negative experiences with medical professionals and questioning medical ways of knowing the body and life course. Undermining biomedical authority took two interrelated forms among the study participants. First, over half had a negative experience with a doctor. Others, whether or not they had a negative experience, questioned biomedical understandings of the life course, health, and diet.

Jill: Unresolved issues and an unnecessary scare

Jill, a nurse in Topeka, Kansas, began experiencing stomach problems and excruciating headaches in 2003. She sought help from several doctors with no success.

I'd been having some issues that'd been unresolved, and I'd been to the doctor. You know, you get in the whole system of: this doctor runs tests, they do this, they do that, they write a prescription, and if that doesn't work they don't know what to do with you. They pass you to another doctor.

As far back as eight or nine years, I had stomach issues. I went to the doctor, they did the scopes and biopsies and they thought I had this, and thought I had that, and did the medications...and by the end of this whole long, drawn out process, they didn't have an answer for me. It was like, "Ok, what am I going to do now?" and they didn't know what to do.

Fast forward, I started having a lot of headaches. He [ear, nose, and throat doctor] said my sinuses were fine, so he sent me to a neurologist. He wanted to put me on migraine medicine. I'm like, "I don't have migraines" and he's like, "Yes you do" and I'm like, "No I don't." He was upset that I wasn't taking the migraine medicine and said we needed to do an MRI...basically to cover his ass."

Here, Jill describes a disagreement with her neurologist over the cause of her headaches and the need for an MRI. The MRI uncovered a cyst in her brain. A frightening series of procedures showed it was benign and unrelated to her headaches. Following that experience, Jill turned to a naturopathic doctor. He diagnosed gluten intolerance, along with other food sensitivities. After eliminating gluten, Jill stopped having migraines, lost weight, and eliminated her digestive problems. As a nurse, she doesn't reject biomedicine entirely. However, she does want others to know Western medicine doesn't have all the answers. The compartmentalized view of the body and deep ties to the pharmaceutical industry lead doctors to overlook root causes of illness. Most physicians, she says, don't emphasize the role of lifestyle and diet in health. Jill has since sent over 25 people to the alternative practitioner who diagnosed her gluten intolerance.

Michael: Taking Matters into His Own Hands

Other participants were disappointed when their doctors failed to address diet. In some cases, medical recommendations worsened problems. Michael's negative experiences with his doctors propelled him to self-diagnosis. He went gluten free four and a half months before the interview.

I got to a point when I got very, very sick. I had to go to the ER. The medication they were giving me... It was like they were [taking] shots in the dark. They didn't know exactly what I had. And the medication they gave me and the recommendations they kept giving me were making it worse. So I got sick of trying to find answers and going week after week after week and having to deal with this, and not getting better. So I decided to take matters into my own hands. The doctor said that it could be many things, but he never talked about gluten. It was kind of my idea that it was an option.

Michael was one of many participants whose doctors were unable to help them. Michael suspected gluten and tried a gluten-free diet; he felt better immediately. He still needed help gaining weight, and consulted a nutritionist, but the drink she recommended made him sicker. "It was frustrating because you were feeling better and you follow a doctor's advice and you get worse and you start wondering, 'What the hell is going on?'"

Michael strongly recommends independent research and self-diagnosis. In the interviews, many participants stressed the important relationship between diet and health. Medical professionals' inability to make such connections make self-diagnosis imperative. Participants criticized biomedicine's view of the body, which precludes awareness of the multifaceted and indirect ways food intolerance can manifest. Doctors' perceived lack of nutritional training, and their failure to connect patient's symptoms to food, become a forceful argument for the value of self-diagnosis and alternative practitioners.

Christy: Questioning Biomedicine's View of the Life Course

Other participants questioned the medical narrative of the "normal" body or life course. Christy, her four children, and several in-laws are gluten free following decades of health problems. She discussed her 70-year-old mother's dramatic improvement after going gluten free.

My mom and I both have had debilitating arthritis. Here she is, in her late 70s, improving. You just don't see that. You see people who are in pain, and misery, and are going downhill, and they think: "It's aging, this is what happens when you age." Well, it's a symptom. It doesn't have to happen. It can get better.

You know, modern medicine is miraculous in what it can do in various stages of people's lives...but in the general huge gray area of everyday misery for almost everyone you know, they're convinced—so the patients are convinced—"Well, you're getting

older.” That’s what they say. That, or “It runs in my family.” Well, what runs in my family is caused by gluten intolerance.

Through such comments, Christy and other participants move beyond a critique of their doctors’ expertise. They challenge underlying assumptions about the life course and the medical approach to the body.

Diagnosing Others

Some gluten-free adherents persistently diagnose those around them with GRDs.

Numerically, this factor represented the fewest research participants: one-third, compared to over half for each of the other two I identified. The small percentage, however, is counterbalanced by these participants’ vocality. Furthermore, participants who persistently diagnosed others overrepresented the first two factors I addressed: experiencing unexpected relief and undermining biomedicine.

All participants talked about their diet to explain their new dietary restrictions, particularly in situations where they were likely to encounter food. Many participants would even suggest the diet to others when they felt it necessary. A common tactic was, “Let me tell you what worked for me.” Rather than outright encouraging others to adopt the diet, these participants armed others with enough information to make their own decisions. Often, the self-reported approach was gentle. The act of describing symptom relief to others can contribute to the expansion of the prototype and the spread of the diet.

Diagnosing others, however, goes beyond talking about the diet with friends and family. A number of participants sought opportunities to promote the diet and the dangers of gluten. These participants often believe gluten is bad for all people, or none can digest the protein sufficiently. These individuals blame myriad “standard American” health problems (at least in part) on the prevalence of gluten in the American diet. Two examples are illustrative here.

Christy: “List all your symptoms”

Christy, as I mentioned earlier, eliminated gluten with her four children. She discussed at length the many people she had approached about the diet. She was convinced her friends’ health problems are gluten-related and strongly urged them to try the diet.

I’m starting to not be able to go out in public. I see little kids with bright red patches on their cheeks, or dark circles, or go to [the grocery store] and see a friend whose kids missed 40 days of school last year, and he doesn’t believe it’s wheat.

She believes gluten disorders are much more prevalent than commonly thought. “The mainstream articles still all say the same thing, [one in 133 have celiac]. Call it what you want: gluten sensitivity, gluten intolerance, celiac...I think out of 133 people, maybe 120 of them should not eat wheat.” She described neighbors to whom she tenaciously prescribed the diet and spoke harshly of them when they refused change. Those who followed her recommendation experienced miraculous recovery. She emphasizes their success as part of her narrative.

Christy’s promotion of the diet extends beyond her social network. When she hears strangers discussing health concerns in public, she speaks up. As a result of one public intervention, she says several people at her yoga studio successfully eliminated gluten.

Christy’s fervent promotion of a gluten-free diet includes an unexpected symptom-relief narrative and criticism of the biomedically “normal” life course. While diagnosing others, she directs them away from biomedicine. By recounting her unexpected relief—and that of those she successfully influenced—Christy advocates an extensive illness prototype. She tells friends, “We can either talk for three hours, or you can go home and write a list of all the symptoms you have and your parents have, and search for those symptoms plus gluten, and see what comes up.” What they will find, she says, is gluten-related problems. When faced with medical crises, the solution should be dietary, not medical. It is as easy as “picking this cereal instead of that cereal; this pasta instead of that pasta. Should I see a therapist, should I be on medication? No,” Christy

says. “Just don’t eat the damn cookie.”

JoAnn: An audience of 700

Like Christy, JoAnn eliminated gluten with her family. JoAnn, who studied microbiology in college, has a scientific interest in why gluten affects so many. She keeps up with medical literature on the topic, but debates it. She disagrees with the diagnostic process, biomedicine’s physiological distinction between celiac disease and non-celiac gluten sensitivity (NCGS), and the published rates of gluten-related disorders (GRDs). She communicates this skepticism and undermines biomedicine. It is good at crisis intervention, she says, but fails in knowledge of diet and lifestyle.

I think probably most of what Americans are facing, at this point, is diet and lifestyle related. And so, for all of that, I think modern medicine is not so good. I’m skeptical of it. And I’m especially skeptical because I see them steer people wrong so much, and try and push them towards pills and interventions that have side effects and risks, when often less invasive approaches—look at how they deal with the gluten issue, it’s a prime example. What do they tell people? “If you think you’re gluten sensitive, *don’t take yourself off gluten*.” So you’re waiting. So...what? So we can get a positive diagnosis? If they don’t need that to get them to do it, just try it!”

Many have gone gluten free on JoAnn’s recommendation. For several years, she has presented about the dangers of gluten at a national vegan conference with an audience of about 700.

When I get there...people come up to me and say, “I went to your talk last year, and you won’t believe what happened to me!” And they tell this whole story, and the doctors, and they missed it...and then they tried going gluten free and everything cleared up! And really what I find is that many people, once they try a gluten-free diet, they don’t see it as deprivation, they see it as a huge blessing. Their quality of life improved so much.”

In her annual talk, JoAnn suggests everyone should be conscious about minimizing gluten consumption. Few people can eat it without consequence; most are gluten intolerant, whether they know it or not. JoAnn’s public promotion of gluten free (GF) includes a self-published cookbook, *Get Off Gluten!*, and a Web site by the same name. Her Web site includes

sections such as “Information your doctor might not have” and testimonies about radical improvement in health after eliminating gluten.

Discussion

Prototype Change in the Gluten-Free Community

My data show that both biomedical and lay GRD prototypes are changing rapidly through ongoing medical research and self-diagnosis. I identify unexpected symptom relief as the mechanism of lay prototype change. Through unexpected symptom relief, dieters are moving gluten free away from its celiac roots.

The celiac prototype is the original gluten-related prototype. “Classic” symptoms of CD are gastrointestinal; as a result, many participants in this study reported their doctors were skeptical of their GRD because they presented non-classic symptoms. Anecdotal evidence suggests participants with symptoms closely matching the celiac prototype—particularly diarrhea, gas, and bloating—were diagnosed more rapidly than those with non-prototypical symptoms. Medical literature also shows many cases of CD escape diagnosis because of atypical symptoms (Sapone et al 2012).

Increased focus on GRDs is changing both the lay and biomedical prototypes. New symptoms are incorporated into both prototypes regularly. The First International Consensus Conference on Gluten Sensitivity identified the top five NCGS symptoms as abdominal pain, eczema, fatigue, headache, and mental confusion (Sapone 2011), reflecting a move away from a narrow, classic GRD prototype.

However, the use of a gluten-free diet to treat non-classic symptoms is not accounted for by recent expansion of the official biomedical prototype. Symptoms presented at the consensus conference do overlap greatly with the lay prototype; for example, fatigue, foggy thinking, and joint pain. However, the conference was held in February 2011 and the official reports from the conference were not published until February 2012 (Robinson 2012; Sapone et al. 2012). Almost

all (97 percent) research participants were gluten free before the revised symptom list was published, and more than half (55 percent) were gluten free before the consensus conference convened.

The broadening of the lay prototype precedes changes to the biomedical prototype. Data from the top medical researchers and study participants suggest the biomedical model is simply catching up to what the lay public already knows. Dr. Alessio Fasano, who co-chaired the consensus conference, said

With gluten sensitivity, we're standing at the same crossroads that we encountered with celiac disease almost 20 years ago. We're just beginning to understand how it affects certain individuals and are now in the early stages of discovering its molecular mechanisms. We do know that it's a different condition from celiac disease, *which is what patients have been telling us for some time now*. [Robinson 2012, emphasis added]

Similarly, several participants' physicians expanded their acceptance of gluten free based on patients' experiences. Christy exemplifies how a patient's unexpected symptom relief can also impact her practitioner's illness model.

I told [my doctor] we got better on the diet....She's seen us get better. We feel better. We look better. Weird things, like hair growing faster, feet growing, nails changing. She's been watching. She said before she watched us go through this recovery, she thought there was a big percentage of her patients who she'd just be never able to help, because of these everyday, chronic, seemingly mysterious symptoms. Now, she's sending people to [a naturopathic doctor]. She's doing food sensitivity tests. She's diagnosed people in her family. She's changed her diet, she's changed her kids' diets.

Despite biomedical inclusion of non-classic symptoms for CD and NCGS, lay and medical models still conflict. The two disagree on some symptoms, as well as use of the diet to treat disorders like schizophrenia and multiple sclerosis (Sapone et al. 2012). Because the lay model seems to be expanding more rapidly than the biomedical one, it becomes a site for conflict between biomedical and lay knowledge.

Expert-driven prototype change is fueled by new research (Hacking 1995). Within gluten

free, however, lay prototype change precedes biomedical change. Unexpected symptom relief is key to the rapid expansion of the GRD prototype. The examples of Matilda, Sandy, and Victoria show how the diet relieved primary symptoms and sensations they had believed to be normal. Fifty-five percent (17 of 31 non-celiac participants) experienced such unexpected relief. Participants realized these symptoms were not normal, but pathological; their conceptualization of gluten disorder grew to encompass both the symptoms they sought to relieve *and* the newly pathologized symptoms. As they narrate their diet experience to others—or suggest the diet based on others' symptoms—these new symptoms are incorporated into the popular illness prototype for gluten disorders. Three participants' experiences exemplify this phenomenon.

Undermining Biomedicine, Subverting the Diagnostic Process

Jill, Michael, and Christy's narratives demonstrate how participants' experiences reinforce the imperative to look outside of biomedicine for their healthcare, whether to alternative practitioners or self-diagnosis. These narratives simultaneously invalidate medical encounters and, through their success, validate self-diagnosis and alternative practitioners.

One way this occurs is through subversion of the diagnostic process. Diagnosis is an important aspect of the doctor-patient relationship. The power to interpret a patient's complaints reinforces the doctor's knowledge, status, and authority (Jutel 2009:279). As we saw with Jill and Sandra, doctors' failures as diagnosticians create an opportunity for patients to question their authority. Such failure is particularly salient when patients realize the simplicity of their condition and improve rapidly through self-diagnosis or under the care of an alternative practitioner.

Diagnosis is also critical for social acceptance and accommodation. In the case of many food intolerances, however, the unclear etiology and symptomology make diagnosis difficult, and—as in the case of gluten—food intolerances are not widely accepted by health care

practitioners as legitimate medical concerns. Medical literature points to gluten free as a fad (Nettleton et al. 2010; Sapone et al. 2012). Medical experts, suggesting the public's susceptibility to trends, are largely dismissive of the diet's popularity. "'Allergy' is currently all the rage, and it is well possible that many individuals are on a GFD for no sound medical reasons" (Sapone et al. 2012:10). Such assertions promote skepticism among medical professionals. As a result, those with food intolerances struggle with lack of a biomedical validation of their experiences; they feel marginalized by health care professionals and in wider society (Nettleton et al. 2010).

My research suggests an alternative approach. Participants claimed medical legitimacy for their conditions and discredited doctors for their failure to correctly diagnose the problem. Few people reported social stigma for lack of an "official" diagnosis. Many used biomedical language to explain their diets and cast themselves as legitimate experts on their bodies. The conflict between the rapidly expanding lay illness prototype and the medical prototype based largely on the classic symptoms serves to further illegitimate medical diagnoses. Participants faulted medical professionals for not keeping pace with lay knowledge of gluten's harm. "Most of the mainstream allergists...you see articles all the time that say, 'there's no need for people who aren't celiacs to go on a gluten-free diet'" said one participant. Mockingly, she added, "It's whatever they learned in school, they won't think any different." Another complained that doctors are "stuck on the gold standard" for diagnosis; she thinks the real gold standard needs to be: does the diet work for you?

Jutel (2009) described diagnosis as "the fulcrum of the medical narrative," the narrative that confers truth and social legitimacy on a patient. By displacing biomedical diagnosis as the legitimator of their illness, participants redraw the boundaries of valid expertise. They find fault with doctors' failure to diagnose and deny the marginalization traditionally associated with lack

of a proper diagnosis. In doing so, study participants help change the meaning of GRDs, moving them from a narrow biomedical diagnosis to a category—a diagnosis—over which participants have ownership.

Diagnosing Others: Shouting from the Rooftops

These women—and the seven others like them—exhibit similarities to participants featured elsewhere in this thesis. Like others, they undermine biomedicine and expand the GRD prototype through their narratives. Unlike other participants, however, they actively work to spread the diet. The persistence of these participants helps explain the rapid spread of the diet to new arenas. Driven by a desire to affect positive change in the wider public, these gluten-free promoters speak at conferences, write books and blogs, and intervene in strangers' conversations. Through them, the gluten-free message—marked by a tense relationship with biomedicine and ever-growing prototype—can be heard far and wide.

The Model

The three factors I identified—changing illness prototype, undermining biomedicine, and diagnosing others—interact to expand gluten free beyond its biomedical roots in celiac disease. Through their illness narratives, participants add to the prototype of GRDs when they recount unexpected relief of symptoms. Participants encourage friends and family to pathologize their symptoms and to recognize their bodily experiences as gluten related. They undermine biomedicine by invalidating biomedical concepts of the body and questioning the competence of doctors, in turn validating self-diagnosis and alternative practitioners. In this way, the diet spreads among lay networks. The third factor helps project the diet to broader audiences. Nearly one-third of participants actively seek to diagnose others and promote the diet widely. These individuals uniformly experienced unexpected symptom relief, and all but one undermine biomedicine in some way. Such promotion of gluten free forcefully promotes an expanded

illness prototype and the validity of self-diagnosis. Together, these three mechanisms constitute a form of lay-driven looping with consequences for the reception of gluten free in society and the doctor-patient relationship.

Self-Ascription and Contested Illness

I have described three critical mechanisms for gluten free's looping. Hacking (1995) predicted an entirely new kind of looping—based not on expert-driven change, but on “self-ascription.” In gluten free, we see self-ascriptive looping at work. The changes in the GFD challenge conceptions of celiac disease and food intolerance as contested illnesses. In the following section, I will outline several ways GRDs *do* conform to other contested illnesses in the literature. I will then describe two consequences of gluten free's self-ascriptive looping that differentiate it from these examples.

Gluten-Related Disorders as Contested Illnesses

Celiac disease has been identified as a contested illness, particularly because patients must struggle for a correct diagnosis (Copelton and Valle 2009). Other gluten-related disorders also fit several key characteristics of contested illness (Swoboda 2006). Like chronic fatigue syndrome (Horton-Salway 2004) and fibromyalgia (Barker 2008), GRDs have a controversial status as a legitimate illness (Ray 2010), an ambiguous etiology (Nelson and Ogden 2008), and disputed status in medical and cultural classification (Knibb et al. 2000). GRDs and other contested illness sufferers confront inadequate medical treatment by seeking outside information and treatment for their conditions, developing lay illness prototypes to understand their disorders (Swoboda 2006:243).

The relationship between lay and medical communities also mirrors other contested illnesses. Sufferers impel scientific research into the disorders (Swoboda 2006:245). Statements from the First International Consensus Conference on Gluten Sensitivity show medical

professionals' response to the increasing numbers of patients claiming GRDs. One conference report said

Sensitivity to gluten may explain a large number of symptoms reported by patients, including abdominal pain, migraine, mental confusion and fatigue, diarrhea, pins and needles and at times even loss of feeling in the limbs. *Driven by increasing numbers of patients presenting with these symptoms*, a panel of international gastroenterologists met in London in February, in the first Consensus Conference on gluten sensitivity. (Naselli 2011, emphasis added)

Similarly, data presented here show medical professionals responding to the broad lay illness prototype. Medical research and clinical recommendations are changing based on patients' reported successes on the diet.

My data show several disjunctures, however. Self-ascriptive looping among gluten-free participants has two ramifications. First, increased popularity of the GFD without medical backing *decreased* social legitimacy. Second, participants use personal experiences to question biomedical practice rather than appealing for greater medical legitimacy and seeking support of doctors. These differences warrant increased scholarly attention to the experience of GRDs.

Specter of the Fad Diet

Lay-driven looping of GRDs has implications for public perception of the disease. Rather than moving toward *more* social acceptance, self-diagnosed specialty diets attract strong backlash. This may be related to the important role of food in society (Nettleton et al. 2010), wherein what one eats is a critical marker of identity. Food avoidance—even when medically necessary—casts a person as picky, self-absorbed, or on the political fringe. The Internet is rife with backlash against gluten free, many making harsh character judgments based on the diet (cf. Campbell 2012).

Without medical consensus to bolster illness claims, gluten-free diets are often perceived as faddish. Participants reported skepticism when they asked for gluten-free items in restaurants

or in social situations. They felt servers discounted their needs as just another diet trend, or saw them as a picky customer wanting attention. One participant said, “There’s also the whole fad diet, which I’m actually really against. Not that I think people shouldn’t be aware of what they eat, but the problem for people who are needing to eliminate it is that other people don’t understand the difference between the two.” Servers dismissed her needs, misunderstanding her as just another picky customer.

Several high profile cases spotlight skepticism in the restaurant industry. In a Facebook post (del Signore 2011), one chef suggested gluten-free patrons do not need the special accommodation, and in fact can eat gluten without any negative effect.

Gluten free is bullshit!! Flour and bread have been a staple of life for thousands, THOUSANDS of years. People who claim to be gluten intolerant [*sic*] dont [*sic*] realize that its [*sic*] all in there [*sic*] disturbed little heads. People ask me for gluten free pasta in my restaurant all the time, I tell em sure, Then I serve serve em our pasta, Which I make from scratch with high gluten flour. And you know what? nothing, NOTHING! ever happens! People leave talking about how good they feel gluten free and guess what, They just had a full dose! Idiots!

Celiac sufferers—both research participants and in the blogosphere—lament the “fad status of the gluten-free diet has robbed them of their credibility” (Myers 2012). Several participants, rather than use the term “gluten” in a restaurant, will tell wait staff they are allergic to wheat. Melissa, who was diagnosed with celiac disease in 2009, said, “Basically I just say I’m deathly allergic to wheat, horrible things happen to me if I eat it. I felt like I was taken more seriously if I used ‘I am deathly allergic.’”

Physiological aspects of GRDs make it difficult to prove real necessity in a restaurant. As participants noted, one challenging aspect of being gluten free is that, usually, the adverse reaction is delayed. It can take hours or days to feel the physical effects of accidental gluten ingestion. For some celiacs, the damage accumulates over weeks or months, and it is nearly

impossible to isolate the source of ingestion.

The phenomenon of self-ascriptive looping results in a particular set of challenges for GRDs. One participant, David, identified the broadened illness prototype as part of the trouble with gluten free. “The gluten symptom picture fits with all these other symptom pictures in a way that makes us seem like we’re another bunch of hypochondriacs. But we’re *not* hypochondriacs.” Without the support of experts who validate categorical boundaries, GRDs are an increasingly nebulous, contested category. As a result, gluten-free adherents—including diagnosed celiacs—must now confront media and public skepticism of the diet.

Looping to a Changed Doctor-Patient Relationship

Unlike other contested illnesses, medical professionals are not the only path to legitimacy for GRD sufferers. Medical research is particularly important in the case of non-dietary disorders because biomedical experts are the gatekeepers to appropriate treatment (Dumit 2006). Research shows contested-illness sufferers constantly strive for medical legitimacy and the corresponding sick role it bestows (Copelton and Valle 2009). For GRDs and other dietary illnesses, however, medical legitimacy is less urgent. Food intolerance leads to lifestyle changes rather than medical intervention, allowing patients to “claim, name, and treat [themselves] as food intolerant” without the support of a doctor (Nelson and Ogden 2008:1044).

Laypeople have expressed skepticism of expert advice “in relation to the health risks associated with food” for several decades (Lupton 2000:209). They use lay sources, such as family and friends, to make dietary decisions. Laypeople have a complex and ambivalent relationship with expert dietary advice. In the face of conflicting expert advice, they trust peers’ experiences and their own bodily knowledge. In the case of GRDs, skepticism of dietary advice spawns skepticism of biomedical practice as a whole.

I suggest food intolerances such as these GRDs create a bridge to transfer existing

skepticism of dietary advice to a wider range of medical encounters. Participants in this study expressed mistrust when doctors discouraged a gluten-free diet, especially when that expert advice conflicted with the expanding lay prototype for gluten-related illness. Not only did they challenge doctors' dietary advice, they called into question the entire biomedical process and perspective on the body.

It is unlikely these patients will leave biomedicine entirely. Studies of complementary and alternative medicine (CAM) show patients use alternative treatments alongside biomedicine. CAM most often serves chronic illnesses, while biomedical practitioners are consulted for acute conditions, diagnostic tests, and physical injuries (Segar 2012). However, what research participants displayed when they undermined biomedicine is the extreme minimization of the role of conventional medical practitioners in their lives. Their experience with the gluten-free diet caused them to reconsider doctors' authority over other areas of their health, as well.

Self-ascriptive looping changed how participants relate to doctors, not only for dietary advice, but for many areas of health. As gluten free continues to grow through the mechanisms I described, it may pull larger populations away from biomedicine as their primary health recourse. The success of gluten free for a wide range of disorders may promote a rethinking of biomedicine's role in varied chronic illnesses, even beyond GRDs. This research supports other calls to understand how "the diminished importance of medical and scientific experts" might impact "experiences of health and illness" (Counts 2011:1-2)

Conclusion

Food intolerances are on the rise in the United States and other Western nations, with recent studies suggesting one-fourth the population of industrialized countries perceive sensitivity (Zopf et al. 2009). In the United Kingdom, figures may be as high as 45 percent (Nettleton et al. 2010:290). While this study cannot be widely generalized to other sites or diets, anthropologists can use these findings to guide future research. The three-part model—undermining biomedicine, broadening illness prototypes, and diagnosing others—propels gluten free's spread. Researchers can use this model to examine other sites and disorders. This study shows we should pay close attention to the growth of gluten free and other such diets, and we should question how the experience of food intolerance might continue to reshape the doctor-patient relationship and challenge the legitimacy of the biomedical approach to the body.

Over the past several decades, social scientists described shifts in the doctor-patient relationship and how patient access to information, alternative therapies, and lawsuits have challenged doctors' authority (Jutel 2009). The experience of gluten free may signal another such shift that merits anthropological attention. Food intolerances such as gluten-related disorders occupy a particular site in the doctor-patient relationship because they do not require diagnosis to precede treatment. Individuals can avoid foods without a diagnosis, yet they also fit within biomedical diagnostic categories. This study calls attention to the effect of self-ascription on the doctor-patient relationship. What is critical is how the experience of gluten intolerance seems to change participants' views of biomedicine and has the potential to reshape the doctor-patient relationship beyond the realm of diet.

Furthermore, scholars can use this study to examine food intolerance as a distinct form of contested illness experience. The case of gluten free suggests that food intolerances can be a

form of contested illness that is an imperfect fit with previous models. On the one hand, we see similar tensions with the medical community and the use of lay information networks. On the other, study participants reframe diagnostic legitimacy. They undermine biomedicine and legitimate self-diagnosis. Increasing medical legitimacy corresponds to social acceptance; in the case of gluten free, the specter of the fad diet has only increased social contestability.

Examining GRDs through the lens of the looping effect helps explain how the category of gluten free changed so dramatically over the last decade. With this force in mind, we can pay close attention to how gluten-related disorders have changed over the past several decades, and what form they will take in the future. Finally, this research provides a framework to examine the growing populations of food-intolerant people in the United States.

Limitations of the Study

This study has several methodological limitations. First, I did not draw a random sample from the gluten-free population. As a consequence, I cannot interpret the high levels of education or unequal gender distribution as anything more than artifacts of my sampling method. I was only able to interview gluten-free people who read bulletin boards, responded to advertisements, and wanted to discuss their diets. I did not speak with many individuals who eliminated gluten without medical necessity (such as weight loss). This may be due to the current stigma against the gluten-free “fad,” or simply because “fad” dieters are less likely to identify themselves to a researcher. Finally, the population of Lawrence is not itself representative of broader populations. Despite these limitations, the findings I present here show the importance of the rise in gluten free. Though I found support for much of my research in the literature, future studies should consider larger and more diverse populations to expand on the research I present here.

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Appendix 1

Sample Interview Schedule

Do you currently follow a gluten-free diet?
How long have you been following the diet?

Have you received a medical diagnosis that requires a gluten-free diet?
"If so, and if you feel comfortable, would you tell me about that? (What were the circumstances? How did you feel about it?)" etc.
If no, have you talked to your doctor about it at all?
Have you received a diagnosis or information from a naturopathic doctor about a gluten-free diet?

How did you first learn about gluten-free diets and/or celiac disease?

Why did you adopt the diet? Tell me about what your life was like when you decided to adopt the diet. What was going on with you, etc.?
Did you try other things like medicines or different diet regimens before going gluten-free? Why or why not?

What do you think your symptoms are indicative of?

What sources do you rely on for information about gluten and the gluten-free lifestyle?
How did you find those sources?
How do you know which ones to trust?

What was the transition like when you adopted the diet?
Which foods were/are the hardest to give up/avoid?
Did any friends and family adopt the diet along with you?
How did your friends and family respond?

How did you explain to others what the diet was and why you were doing it?
Do you explain the diet in different ways to different people? (e.g. Family vs. Coworkers vs. Waiter at restaurant)

How do you feel if/when you eat gluten?

Have you stayed on the diet?
Why did you go off the diet? Why did you go back on?
What was it like going off/on the diet?

Has anyone you know adopted the diet since you did?

Do you know of any gluten-free forums or support groups? Do you participate in them? What has your experience of them been?

How has your social experience changed since you adopted a gluten-free diet?

Increase in popularity of the diet, availability of food, acceptance of dietary needs, etc.?

Where do you do your grocery shopping?

Do you do anything else for your health? Dietary, non-dietary?

When something is wrong (health wise), what is your first recourse?

Where do you get your health information?

Do you think that gluten intolerance/sensitivity/celiac is becoming more prevalent?

Do you think that everyone should avoid gluten?

What would you say to someone who is considering a gluten-free diet?